

TESTIMONY OF
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Everyone in this room either is, or knows someone who is, caring for a relative suffering from Alzheimer's disease. Alzheimer's disease has devastating effects on both patients and on the families who care for them. Drugs produce only modest improvement and the possibility of curing or preventing Alzheimer's disease remains far in the future. In the meantime, as the population continues to age, the financial and emotional cost to patients and families as well as the cost of the federal health care budget, continues to grow.

Many caregivers become overwhelmed and find it necessary, much against their sense of what is right, to place their relatives in nursing homes. The problem is that no matter how good a nursing home is, it cannot provide patients with love. Only their families and the people who are close to them can provide true love and caring, not manufactured and not per diem. You cannot buy that. Now, it costs the taxpayer between \$30 and \$70 thousand a year to keep a person in a nursing home. But - for a lot less, we can keep our elderly relatives at home and we can keep our families together. So what we need is a way to help families to keep their loved ones at home.

At NYU, we have shown, with a scientifically rigorous trial, what common sense might suggest is the way. We proved that counseling and support of caregivers and their families is an extremely effective treatment. More than 400 husbands and wives of patients with Alzheimer's disease have enrolled in the NYU Spouse-Caregiver Intervention Study since it began in 1987. Using the kind of design usually reserved for trials of new drugs, we randomly assigned subjects to either a treatment or a control group.

The treatment has two goals: first, to make it possible for spouse-caregivers to do what almost all of them say they want to do - to postpone or avoid placing their husbands and wives in nursing homes; and second, to reduce the negative impact of caregiving on the caregiver.

Because every family has different needs, the treatment includes individual custom-tailored counseling. Because most caregivers would benefit from more understanding and help from their families, the treatment includes family counseling. Because Alzheimer's disease can last for many years and its effects change over time, the treatment is not time-limited.

In the first four months after enrolling in the study, caregivers in the treatment group had two counseling sessions alone with a counselor and four counseling sessions with selected family members. A vital component of the treatment is that counselors continue to provide support for caregivers and their families for the duration of the disease. Counselors are available to help caregivers and their families deal with crises and with the changing nature of the patient's symptoms, to provide information and referrals for additional help, and help them understand and manage the patient's behavior. The treatment also required caregivers to agree to join support groups that met weekly.

Caregivers in the control group received the support that had been routinely offered to caregivers at our center which included resource information and help when they requested it, but no formal counseling.

What were the results? We found that caregivers in the treatment group were able to postpone placing patients in nursing homes for about a year longer than caregivers in the control group - the median difference was 329 days! The treatment was most effective for caregivers of mildly to moderately

demented patients, for whom nursing home placements is least appropriate.

The well-being of the caregivers also improved. Many caregivers suffer from symptoms of depression. While caregivers in the control group became increasingly depressed after they entered the study, caregivers in the treatment group did not. In addition, caregivers in the treatment group grew closer to their families and expressed increasing satisfaction with the emotional support they received. This was not true of those in the control group. Moreover, caregivers in the treatment group were significantly better able to tolerate and manage the behavior of the patients, which undoubtedly resulted in their providing them with a better quality of care.

The study at NYU showed, without a doubt, that counseling and support helps families keep Alzheimer's patients at home. It is clear that the availability of generous, humane long term competent emotional support and referral to high quality community resources can make a huge difference.

What does it say about us as a society if we are not prepared to support the family so that it can care for its members as they age? The ability of a spouse to care for his or her ill partner is often enhanced by the contribution of their adult children. These adults often in mid-life, were torn by the conflicting needs of parents, children, their own spouses and their own personal aspirations. Thus the impact of the disease trickles down to all members of the family. It is not likely that any family will be exempt from the role of caregiving. We need to find ways to provide the kind of help that was found to be so effective in the NYU Spouse-Caregiver Intervention Study to all the family caregivers who need it. We need to find a mechanism for paying for care at home that doesn't drain the family resources. The challenge is to convince those who provide and pay for health care of the value of counseling and support for family caregivers.

The National Institute of Aging has recently provided us with added funding for a Caregiver Core, a major research resource that will also provide support and counseling to all caregivers who are responsible for patients at the NYU-Alzheimer Disease Center. WE are convinced that the well-being of caregivers is essential to the well-being of patients. I believe that the model that was so successful in helping Alzheimer's disease caregivers at NYU can also be an effective part of the treatment of any chronic illness that creates a need for long-term care.